



Family Health *Dataline*

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In this issue we review a report prepared in December 1992 by Stuart Dick, R.D., titled "An estimate of the number of children with special health care needs in the state of Alaska."

- The prevalence of 12 activity-limiting conditions in Alaska was 64-115/1000 children age 0 through 20 years.
- The prevalence of activity-limiting conditions was highest among Alaska Natives and lowest among blacks.
- The prevalence of activity limiting conditions was highest in the Yukon-Kuskokwim Delta and lowest in Anchorage.

Introducing the Family Health *Dataline*

Greetings Colleagues:

I am pleased to introduce this first issue of the Section of Maternal, Child, and Family Health's *Dataline*. We have been working hard over the past few years to learn more about the health status of different populations in Alaska and the programs and services that are most effective in assisting target groups and the population as a whole. We believe it is critical to share what we have learned with other health professionals, so that together we can use this information on behalf of the Alaskans we serve. Topic areas we hope to address include the problems and concerns of women in Alaska as they seek to have healthy babies, the nutritional status and problems of children in the state, and the realities surrounding the issues of women's health care, special needs children, and domestic violence. The Family Health *Dataline* will be produced monthly and will feature one to two topics each issue. We welcome your input regarding the usefulness of the Family Health *Dataline* and ideas for improving it as we go along. The families of Alaska need us all working together and sharing our knowledge and resources to ensure we provide them, in a quality and cost-effective manner, the assistance and support they need to achieve their goals. I hope the information we provide contributes to that effort.

*Karen E. Pearson, Chief
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The Prevalence of Children with Special Health Care Needs in Alaska

Introduction

Children with special health care needs (CSHCN) constitute a large but poorly measured segment of the population in the United States. Previous research of CSHCN has traditionally looked at children with health conditions expected to be of long duration, generally defined as longer than 3 months (1). Examples of such conditions include deafness, speech defects, diabetes and asthma. More recent thinking has focused on the implications of specific conditions to individuals. For example, in 1990 the Supreme Court ruled that the Social Security Administration must determine a child's functioning in the areas of cognition, communication, motor abilities, social

abilities, and patterns of interaction to determine eligibility for services; the specific condition was largely irrelevant (1).

We present the results of a study conducted in 1992 by Stuart Dick, RD, titled "An estimate of the number of children with special health care needs in the State of Alaska." This study provides one of the first well-researched estimates of this population in Alaska. It also raises important issues involved with determining the prevalence of CSHCN and the implications such estimates have for program development and planning.

Methods

Two national studies cited by Dick provided prevalence estimates for specific chronic conditions:

Gortmaker SL, Sappenfield W (2).

Data source: Literature review.

Conditions reviewed: Arthritis, asthma, autism, central nervous system injury, cerebral palsy, chronic renal failure, cleft lip/palate, congenital heart disease, cystic fibrosis, diabetes mellitus, Down syndrome, hearing impairment, hemophilia, leukemia, mental retardation, muscular dystrophy, neural tube defect, phenylketonuria, sickle cell disease, seizure disorder, visual impairment.

Prevalence estimate: 133 chronic conditions/1000 children 0 through 20 years of age.

Newacheck P, Taylor W (3).

Data source: 1988 National Health Interview Survey.

Conditions reviewed: Anemia, arthritis, asthma, blindness and vision impairment, cerebral palsy,

deafness and hearing loss, diabetes, frequent diarrhea/bowel trouble, digestive allergies, frequent ear infections, eczema and skin allergies, epilepsy and seizures, frequent or severe headaches, heart disease, musculoskeletal impairments, respiratory allergies, sickle cell disease, speech defects, other.

Prevalence estimate: 307.6/1000 (31%) children under 18 years of age have at least one of approximately 68 chronic conditions.

Dick applied the prevalence estimates from these two studies for an abbreviated list of conditions felt to be activity-limiting (not further defined) to the population in Alaska (1990 census). Two exceptions to this method existed: diabetes rates were estimated from data collected by the Alaska Division of Public Health, Section of Epidemiology, and fetal alcohol syndrome rates were estimated from an unreferenced study conducted by the Indian Health Service in Alaska. By adding together individual prevalence estimates, Dick obtained an overall prevalence estimate for activity-limiting conditions among children age 0

through 20 years of age in Alaska. He specifically excluded blindness, developmental delay, Down syndrome, emotional/behavioral problems, heart disease, learning deficits, and mental retardation.

Race-specific prevalences for whites and blacks were calculated from the reports mentioned above. Prevalences for American Indian/Alaska Natives (AI/AN) were calculated from records maintained by a physician who specialized in evaluating children with serious chronic conditions at the Alaska Native Medical Center in Anchorage. For persons 0 through 20 years of age, Dick estimated that 70%, 20%, and 5% were white, black, and AI/AN, respectively.

Results

The overall estimated prevalence of 12 activity-limiting conditions in Alaska during 1990 was 64 to 115 per 1000 children 0 through 20 years of age (Table 1). The most common conditions were asthma, speech defects, deafness and hearing loss, and musculoskeletal conditions.

Table 1. High and low estimated prevalences for activity-limiting conditions per 1000 children 0 through 20 years of age; 1990, Alaska.

Condition	High	Low
Arthritis	4.6 n	2.2 g
Asthma	42.5 n	10.0 g
Cerebral palsy	2.5 g	1.8 n
Deafness and hearing loss	16.0 g	15.3 n
Diabetes	2.0 a	2.0 a
Epilepsy/seizures	3.5 g	2.4 n
Fetal alcohol syndrome	1.7 a	1.7 a
Musculoskeletal conditions/paralysis	15.2 n	2.1 g
Neural tube defects	0.5 g	0.5 g
Phenylketonuria	0.1 g	0.1 g
Speech defects	26.2 n	26.2 n
Traumatic brain injury	0.05 g	0.05 g
Total	114.82	64.32

n=Newacheck/Taylor

g=Gortmaker/Sappenfield

a=Alaska specific rate

The prevalence of activity-limiting conditions was highest among AI/AN and lowest among blacks (Table 2), primarily because of differences in the prevalence of deafness and hearing loss, epilepsy/seizures, and fetal alcohol syndrome.

Depending on the racial composition of different census areas in the state, the estimated number of children with activity limiting conditions age 0 through 20 years of age varied from 6,354 in the Anchorage region to 521 in the northwest region; the percentage of children with activity-limiting conditions varied from 9.8 in the Yukon-Kuskokwim Delta to 8.3 in the Anchorage region.

Table 2. Race-specific prevalence estimates of activity-limiting conditions per 1000 children 0 through 20 years of age; 1990, Alaska.

Condition	White	AI/AN	Black
Arthritis	4.5	3.4	5.4
Asthma	10.0	10.0	10.0
Cerebral palsy	1.9	3.5	0.5
Deafness and hearing loss	17.7	32.0	6.0
Diabetes	2.4	0.4	2.4
Epilepsy/seizures	2.5	7.0	2.3
Fetal alcohol syndrome	1.7	4.2	1.7
Musculoskeletal conditions/paralysis	15.9	15.9	10.5
Neural tube defects	0.5	0.5	0.5
Phenylketonuria	0.1	0.1	0.1
Speech defects	25.9	26.2	33.5
Traumatic brain injury	0.05	0.05	0.05
Total	83.1	100.1	72.8

Discussion

There are several important issues raised by Dick's analysis. Despite extensive research on the subject, no uniform definition for CSHCN exists. Overlapping but distinct sets of disorders are included in the two articles used by Dick and Dick himself has defined a third set. In particular, several prevalent disorders, including vision impairment and mental retardation (the second and third-most prevalent conditions in one article [2]), and developmental delay were not included in Dick's analysis. Other articles use other sets of conditions to estimate the prevalence of CSHCN (4). One study (5), using the 1988 National Child Health

Survey, estimated the prevalence of developmental, learning, and emotional problems among children <18 years as 4%, 6.5%, and 13.4%, respectively.

In most articles, including the two used by Dick, there is no definition for the specific conditions which CSHCN have. A study not referenced by Dick defined hearing impairment as a "bilateral pure-tone hearing loss that averaged 40 dB or worse unaided in the better ear at frequencies of 500, 1000, or 2000 Hz" (6) and found rates of hearing impairment 1/16 as great as Dick's referenced articles.

Although Dick attempted to include only conditions which might result in activity limitation, he made no attempt to determine the proportion of children with a condition to whom this term applied. An article not used by Dick which also examined data from the 1988 National Health Interview Survey found that if only children whose condition had lasted or was expected to last >3 months and caused limitation in activity were included the prevalence dropped from 31% to 5.3%. (7) The prevalence of children with a condition which prevented engaging in their major activity was 0.6%. In addition, Dick did not determine the impact of conditions on individuals or the health care system. Measures of impact might include hospitalization and physician contact rates (3); cognition; age of onset, duration, and expected survival; and physiologic functioning (1).

For most conditions Dick was unable to identify Alaska-specific prevalence rates. This resulted from a lack of data linkage between agencies and the lack of uniform hospital discharge data reporting. These problems continue to hinder accurate population-based disease and disability estimates today and remain high priorities for the Alaska Division of Public Health. In addition, Dick recognized the need for local assessments of the prevalence of CSHCN since this may vary between communities.

The magnitude of medical care required by the population of CSHCN far surpasses the funds available at the Section of Maternal, Child, and Family Health (MCFH) through such programs as the Health Care Program for Children with Special Needs. In addition, money available to this

program for purchasing services has decreased by 50% during the past three years. For these reasons, the Section of MCFH is working with health care providers and families to identify other funding sources such as Medicaid, the Social Security Administration, and pooled risk insurance policies.

Agencies outside of MCFH may be better able to provide the comprehensive services, including case management, rehabilitation, mental health, and residential care, often required by CSHCN. For example, one report suggests that Medicaid may be better able to provide comprehensive services than either private health maintenance organizations or private insurers (8).

As health care reform progresses,

it is essential that accurate and reproducible data is collected with which to monitor trends, predict needs, and allocate resources. Based on this information, the health care community can most appropriately address the health care needs of CSHCN.

Contributed by: Brad Gessner, M.D.

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